

# **The North Dakota Autism Spectrum Disorder (ASD) Database**



Kodi Pinks, MPH  
Autism Database Administrator  
Division of Children's Special Health Services  
North Dakota Department of Health



# What do we know about Autism Spectrum Disorder in North Dakota?

- According to the Department of Public Instruction (DPI), the data below represents the number of individuals identified with autism through the educational system

- ☐ December 2016: **1,174**
- ☐ December 2015: **1,031**
- ☐ December 2014: **942**
- ☐ December 2013: **837**
- ☐ December 2012: **786**
- ☐ December 2011: **718**
- ☐ December 2010: **627**



# What is the Autism Spectrum Disorder Database?

- In 2013, the North Dakota State Legislature passed a law (North Dakota Century Code 23-01-41) that requires the North Dakota Department of Health (NDDoH) maintain a database of **all** individuals diagnosed with ASD
- The purpose of the database is to:
  - ☐ Complete epidemiologic surveys
  - ☐ Research and analysis
  - ☐ Provide services to individuals with an ASD



# Requirements of North Dakota Century Code (NDCC) 23-01-41

- Must include a record of ALL reported cases of autism
- Collect any additional information determined relevant by NDDoH
- Convene an expert panel to establish criteria regarding who is qualified to report cases of ASD into the database
- Individual must be diagnosed using the most recent edition of American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders



# NDCC Requirements Continued

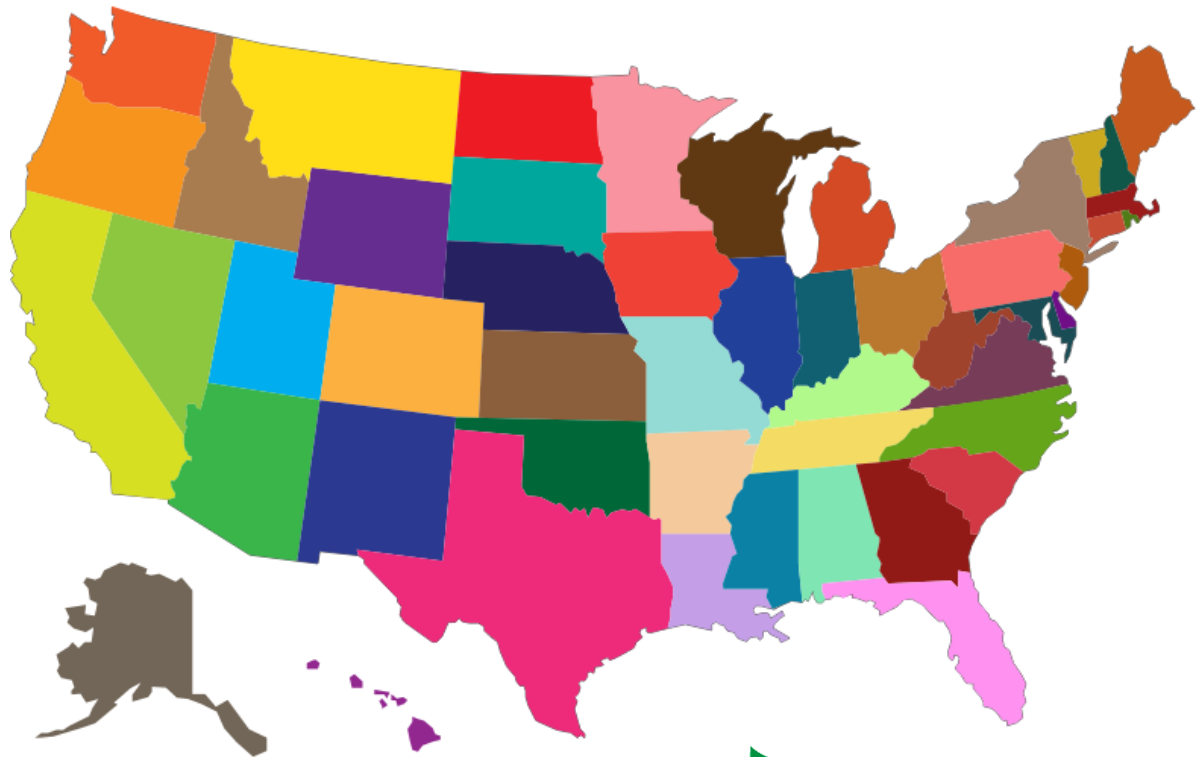


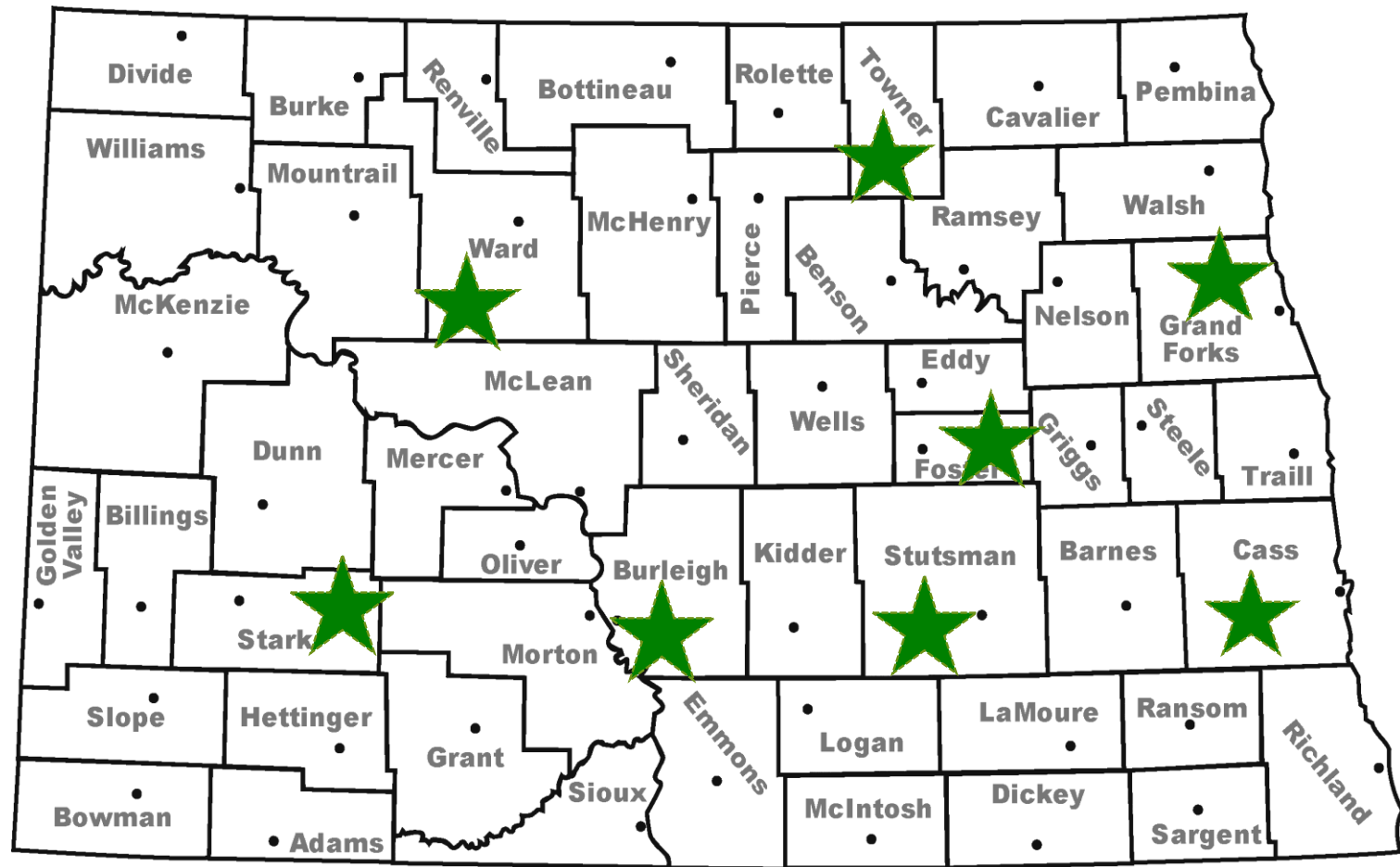
- Must include a complete physical evaluation of the reported individual by a licensed physician
- NDDoH shall adopt rules for mandatory reporting requirements
- NDDoH shall keep confidential records of the database; however, these records may be provided to other state agencies as necessary in order to fulfil the purposes of the database. Any receiving state agency must treat the records as confidential as well

# Comparison to Other State Autism Registries

NDDoH staff researched information from other states that have autism registries

- ☐ Delaware
- ☐ Indiana
- ☐ New Hampshire
- ☐ New Jersey
- ☐ North Carolina
- ☐ Rhode Island
- ☐ Utah
- ☐ West Virginia





The counties the Expert Panel members represented



# Autism Spectrum Disorder Expert Panel Meeting October 23, 2014

- Panel raised concerns about language used in NDCC 23-01-41 was too restrictive
- Panel recommended that the following areas in the NDCC be addressed during the 2015 legislative session before the ASD database is functional
  - ☐ Criteria for qualified reporters
  - ☐ Physical evaluation
  - ☐ Person filling out the report form





# Recommendations by the Autism Spectrum Disorder Expert Panel

## Qualified reporter:

- Rather than: a doctoral-level professional who is licensed, credentialed, and experienced in the field of ASD, including intellectual testing and other formal, evidenced-based assessments for ASD
- Panel recommended: physicians, psychologists, and other masters-level diagnosticians who are trained, licensed, and credentialed to diagnose ASD

## Complete physical evaluation:

- Rather than: including a complete physical evaluation for ASD reporting
- Panel Recommended: reporter indicate whether a complete physical evaluation was performed as part of the diagnostic process for ASD
  - In addition to physicians, licensed independent practitioners may also perform physical evaluations

## Person filling out report form:

- Panel recognized: the person reporting into the database could be different from the diagnostician
- Panel Recommended: A reporter's designee also be allowed to fill out the report form

# Follow-Up to the Expert Panel Meeting

- Researched language used in other states about autism registries
  - ☐ Delaware
  - ☐ New Hampshire
  - ☐ New Jersey
  - ☐ Utah
- Drafted new bill language based off of research and the ASD expert panel recommendations
  - ☐ Drafted bill was given to Senator Heckaman
- Drafted bill was submitted to Legislative Council
  - ☐ SB 2176 was created



# Legislative Session 2015

## Senate Bill 2176

- The department shall require that the reporter be a physician or psychologist or any other licensed or certified health care professional who is qualified by training and by licensure or certification to make the diagnosis of ASD
- Indicate whether a complete physical evaluation was performed by a licensed independent practitioner as part of the diagnostic process for ASD
- A reporter who makes the diagnosis an individual is affected with ASD, or the reporter's designee, shall report this diagnosis in the form or manner prescribed by the state department of health

# Timeline of Legislative Events

- Introduced and referred to the Senate Human Services Committee on January 12, 2015
  - ☐ Department provided testimony on January 21, 2015
  - ☐ Reported back as, do pass with 43 yeas and 0 nays
- Introduced and referred to House Human Services Committee on February 20, 2015
  - ☐ Department provided testimony on March 24, 2015
  - ☐ Reported back as, passed 86 yeas and 3 nays
- Sent to Governor for signature



# Administrative Rules Process

- Drafted Administrative Rules
- Full public notice and proposed rules given to the ND Legislative Council and State Health Council
  - ☐ May 14, 2015
- Public notice written and sent to all county newspapers
  - ☐ May 27, 2015
- Public hearing followed by a 10-day comment period
  - ☐ June 29, 2015
    - Two people outside of the NDDoH attended the hearing but made no comments
    - Received one written comment during the 10-day comment period that was in support of the proposed rules



# Administrative Rules Process

- Proposed rules sent to the Attorney General (AG) for a legality opinion on July 17, 2015
  - ❑ AG's opinion received on July 31, 2015
- AG's opinion submitted to the State Health Council for final adoption
  - ❑ Testified at the State Health Council meeting on August 11, 2015
- Adopted rules were submitted to Legislative Council for publication in the Administrative Code
  - ❑ August 12, 2015
- The proposed rules presented to Legislative Council Administrative Rules Committee
  - ❑ Testified on December 7, 2015
- Legislative Council updated Administrative Code
- Administrative Code became effective January 1, 2016



# Outreach Activities and Education

- Created and disseminated ASD Database brochures for providers and families
  - ☐ Health systems
  - ☐ Family advocacy groups
  - ☐ Local public health units
  - ☐ County social service offices
  - ☐ State agencies
- Health Advisory went out through the ND Health Alert Network (HAN) on February 3, 2016
- Notification went out to ND practice boards





# Concerns Expressed by Mandatory Reporters

- NDDoH received concerns expressed by mandatory reporters regarding the reporting of ASD into the database
  - ☐ Perceived ethical violations based on mandatory reporters code of ethics
  - ☐ ASD report form (SFN 60804)



# Addressing Mandatory Reporter Concerns

- NDDoH leadership was notified
- Consulted with the Assistant Attorney General, Claire Ness
- Claire Ness consulted with attorneys representing mandatory reporter practice boards
- After the consultations, Claire Ness gave her legal view of the reporting mandate
- NDDoH requested the practice boards' positions on the reporting mandate

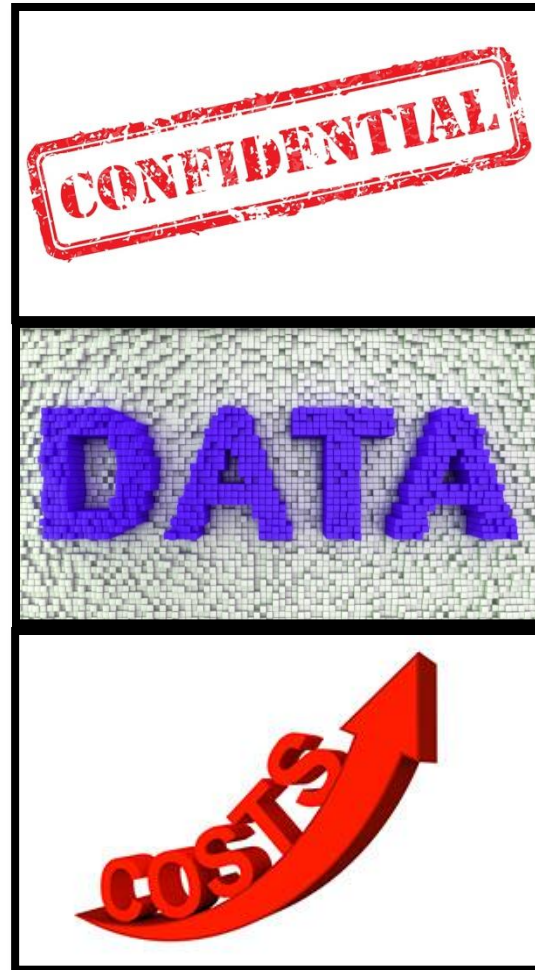
# Legislative Session 2017

## Senate Bill 2241

- **Section 1, Part 3c** - The database must be searchable and allow a reporter to update or amend the diagnosis or status of a previously reported case of autism spectrum disorder
- **Section 1, Part 4a** - The reporting requirements must distinguish between mandatory and optional reporting fields and must allow a reporter to decline to provide mandatory reporting data if the reporter files an articulable rationale
- **Section 1, Part 4c** - A provider who violates this subsection may be subject to a civil fee, not to exceed one hundred dollars per occurrence
- Although the department may provide these records to other state agencies as necessary to effect the purposes of this database without regard to the confidential nature of the records, the records may not include personally identifiable information

# Concerns with Senate Bill 2241

- Section 1, Part 3c
  - ☐ Confidentiality
  - ☐ Data quality
  - ☐ Security access and management
- Section 1, Part 4a
  - ☐ Data quality
- Section 1, Part 4c
  - ☐ Fiscal impact



# Timeline of Legislative Events

- Introduced and referred to the Senate Human Services Committee on January 16, 2017
  - ☐ Department provided neutral testimony on February 8, 2017
  - ☐ Reported back, do not pass on February 14, 2017
- Second reading , failed to pass (yeas 0, 46 nays)



# What About HIPAA?

- HIPAA contains a specific provision authorizing covered entities to disclose protected health information (PHI) as required by law
- HIPAA also provides that PHI may be used and disclosed to public health authorities without authorization from the individual or from the individual's parents/guardians for public health activities



# Who is a Mandated Reporter?

- A physician, psychologist, or health care professional who is qualified by training and licensure or certification to make the diagnosis of ASD
- Mandatory reporters include:
  - ☐ Physicians
  - ☐ Psychologists
  - ☐ Nurse Practitioners
  - ☐ Clinical Nurse Specialists
  - ☐ Licensed Independent Clinical Social Workers
  - ☐ Licensed Professional Clinical Counselors





# Who Should Be Reported Into the Database?

- Mandatory reporters are required to report any patient or client of theirs who has a confirmed case of ASD into the database
  - ☐ Providers cannot report for
    - Suspected cases of ASD
    - Individuals with only an educational determination
- Individuals need to be:
  - ☐ North Dakota residents or whose parent is a resident of North Dakota
  - ☐ Diagnosed with ASD per DSM criteria



# Reporting Requirements

- Under ND Administrative Rules:
  - ☐ Mandatory reporters have 30 days to report newly diagnosed individuals to the NDDoH
  - ☐ For individuals previously diagnosed, mandatory reporters have 30 days of the individual's first patient or client encounter with the reporter to report, or 30 days of the effective date of these regulations to report, which ever is later
    - Reporting is required for any patient or client seen by a mandatory reporter on or after January 1, 2016

# Are There Repercussions for Not Reporting?

- Under NDCC 23-12-07, a person who does not comply with a mandatory reporting requirement, such as the reporting of ASD, is guilty of an infraction
  - ❑ The penalty for an infraction is a fine up to \$1,000
  - ❑ A second infraction within the same year may be treated as a class B misdemeanor



# Progress to Date

- To date, **348** ASD cases have been reported to the department
- Several ASD data reports have been developed and shared at:
  - ☐ ASD Task Force meetings
  - ☐ Annual ND ASD Conferences
  - ☐ Medical Advisory Council & Family Advisory Council meetings
- ASD data inquiries have been made by :
  - ☐ Legislative Council
  - ☐ Family/advocacy groups
  - ☐ Researchers

- Remember just one thing...
  - ❑ the ASD Database is a new program



- The program may need to evolve in order to be successful
  - ❑ Might not get it right the first time
  - ❑ It takes time for meaningful change

# Questions?

